Transcript Details

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APOL1 Screening and Early Detection: Patient and Clinician Perspectives

Announcer:
Welcome to *KDIGO Conversations in Nephrology.* This episode titled, “APOL1 Screening and early detection: Patient and Clinician perspectives,” is provided by KDIGO and supported by Vertex. Here’s your host, Dr. Kirk Campbell.

Dr. Campbell:
Hello and welcome to KDIGO Conversations in Nephrology. I'm Dr. Kirk Campbell, chief of the Renal Division at the University of Pennsylvania. Joining me to discuss APOL1 screening and early detection are two incredibly knowledgeable guests. We'll have the patient and clinician perspectives from Mr. Joshua Albright and Dr. Titilayo Ilori. Joshua Albright is a kidney health advocate, international public speaker and student at Georgia State University who's living with APOL1 kidney disease. He's an advocate for NephCure Kidney International and brand ambassador for the American Kidney Fund. Josh has received numerous awards for his impact on kidney health. Dr. Ilori is an assistant professor of medicine, nephrologist, and clinical researcher at Boston Medical Center and Boston University. She's focused on epidemiology and modifiers of APOL1 kidney disease and the care of patients with APOL1 Kidney Disease. Welcome to you both.

Dr. Ilori:
Thank you very much, Kirk.

Joshua Albright:
Thank you, Kirk for introducing me. Appreciate you guys for having us.

Dr. Campbell:
Great. Great. So, let's begin a discussion with the general awareness around the significant public health issue. What should patients, families, and the wider community know about APOL1kidney disease? Josh, let's start with you.

Joshua Albright:
I think first thing to mention is that I feel like it's just something that not a lot of people even understand what APOL1 one is. Before I was diagnosed, I was not familiar with it at all. No one in my entire family was also familiar with the term as well or even exposed to the information of how so many African American people or people of West African descent are susceptible to contracting APOL1 or having the genetic variation. And I think it answers a lot of questions that we see and the disparities with the kidney disease issues. But it's just not a lot of information for people to understand as to why sometimes these kidney diseases and these health issues are more prominent in our communities and I think just more common conversations should be normalized. So, that there's more information and understanding between people who are more likely to diagnose APOL1 kidney disease.

Dr. Campbell:
Great perspective. And Dr. Ilori?

Dr. Ilori:
Thanks for that question, Kirk. So, a paper by one of our colleagues Dr. Umukueje really encapsulates the answer. And here,

community members were interviewed about APOL1. And the title of the paper is really the answer to your question. They said, “Why are you just now telling us about this?” And that reaction really captures what I've seen clinically in my research and in community engagement discussing with patients and with community members, their response is often the same. Why don't people affected know about this disease? Why are we not talking about this at family dinners at Thanksgiving and in everyday conversations? Why isn't this being passed down from matriarchs and patriarchs of our families. People want to know, how do I get APOL1 disease? How can I pass it on to my offspring? How can I be tested and what can I do if I have this disease?

Dr. Campbell:
Yeah. Thanks so much for that. So, we know that access to testing is quite variable around the world. Dr. Ilori, what is the overall availability for testing in low resource and high resource settings?

Dr. Ilori:
So, when it comes to APOL1 testing, access really depends on where you are. In high resource setting, testing has become more available, but it's still not routine. It often depends on whether your doctor knows about it, whether your hospital offers it or if your insurance will cover it. But in low resource setting, the picture is very different. There is little or no access to genetic testing outside of research studies or charity programs, and even though the burden of disease is high in this communities, so many people do not have access to testing, and this is why testing matters because the people most at risk may never have the opportunity to be tested. We need to think of not just making testing available but making sure that the right support and follow-up care is in place so that the results are meaningful and fair.

Dr. Campbell:
If you're just tuning in here, listening to the KDIGO podcast on APOL1 screening and early detection patient and clinician perspectives. I'm Dr. Kirk Campbell and I'm speaking with Dr. Titi Ilori and Mr. Joshua Albright. So, who needs to be tested and what is the optimal time for testing? Dr. Ilori?

Dr. Ilori:
So, there's no gold standard for who should be tested for APOL1 kidney disease, but there's always a suggestion for testing. And interestingly, we really do need to consider pros and cons of testing. I think one big challenge is that right now testing may not have any clear actionable management steps and therein lies the big challenge of testing. And so, although there's insufficient evidence for testing at the population level, testing has been associated with greater blood pressure reduction, increased screening for kidney disease, and self-reported behavior changes. We may want to consider testing in the following scenarios as clinician: one where counseling is available, two, when the suspected risk of APOL1 variants in an individual with kidney disease, if it's a potential living donor, if it's a person with relatives with APOL1 high risk. If where chronic kidney disease care and screening are available, where testing may be able to alleviate anxiety and help in reproduction decision making and in at-risk populations. Individuals of African ancestry or in a highly admix population. And finally, of course, if there's no harm in testing the individual.

Dr. Campbell:
Thanks, Dr. Ilori. Can you also comment on using APOL1 testing for precision-based care delivery and risk stratification?

Dr. Ilori:
That's a fantastic question, Kirk. APOL1 testing is emerging as a powerful tool for personalized kidney care, especially in people of recent African ancestry who carry two copies of the high-risk variant. It helps identify those at greater risk for rapidly progressive non-diabetic kidney disease and will allow for more tailored monitoring treatment and counseling. In precision medicine, knowing a patient's APOL1 status can help us refine prognosis, guide earlier interventions, and inform decisions around kidney transplantation. For donors, APOL1 genotype can predict graft outcomes. It can help optimize donor selection and post-transplant management. It also supports risk stratification, family counseling, and lifestyle planning for those at higher risk. That said, testing isn’t yet routine. The challenges include limited clinician awareness, variable availability, and the need for genetic counseling to help patients interpret results. We know there are lots of emerging treatments targeting APOL1 function, and these highlight the growing potential for genotype driven care. In short, testing is important. It holds great promise for delivering personalized risk informed kidney care, but it's got to be paired with counseling, with thoughtful implementation, and with equitable access.

Dr. Campbell:
That's great. Let's talk a bit about the psychological impact of genetic testing and what's needed for holistic care of patients with APOL1

Kidney disease. Josh, can you tell us a little bit about your experience getting tested? What concerns did you initially have about getting the APOL1 genetic test?

Joshua Albright:
So, for me personally, it was actually no concerns jumping into being APOL1 tested because being genetic testing actually opened up the opportunity for me to be placed in a clinical trial. So, there was a lot of opinions from both sides when I sat down with my family about, you know, maybe the pros and cons from potentially being in a clinical trial. But with genetic testing, I think it was necessary for me to move forward, to weigh my options with my treatment and with my care. When I first heard about APOL1 and got tested my initial reaction was, you know, the shock and the fear. I live in a household with seven other people; we're a family of eight. So, it was just a lot of questions running through my mind about my future, my family, my life goals, and I just remember wondering how would this affect my opportunities? How would this affect my life? Will it limit me in a certain way? Will it limit my family in a certain way? And for me and so many other patients, it wasn't just a medical thing, it's also very mental. It kind of weighs on you heavily emotionally. The sense of security that you kind of have may shift because you have this thought now that's placed on you that you have to worry about. And me being diagnosed at just turning 18 years old, it was just extreme adjustment days where the anxiety was very unknown. It was just tough. Just kind of placing that new stigma on yourself and your family, knowing that you could be at an increased risk for something like FSGS or another kidney disease.

Dr. Campbell:
Thanks so much for that, Josh. And what support did you get when the results were provided? Just in terms of family genetic counseling, was there a detailed explanation of what the results meant for you and your treatment options?

Joshua Albright:
For me, I think what made the difference was my support system. My family obviously was there but as well as my doctor and the care team. We took time to explain things, to go step by step in a way that I can understand it. As an 18-year-old being recently diagnosed, it's probably tough to understand all what's going on. But they did a great job at just explaining it to me and being there for me. And like I said, I was able to be placed in a clinical trial and just the layer of support that I was able to get, not only mentally, but physically just checking on me and explaining each step to me, giving me the reassurance. And I felt like I was contributing to something that could potentially help myself, maybe help my family or help others in the future. Just for more research on APOL1.

Dr. Campbell:
Yeah, no, thanks so much. And Dr. Ilori, can you share your perspective?

Dr. Ilori:
So, I think, as Josh has really told us today, there is a psychological impact of getting genetic testing, and this is real for patients and their families. Many people worry about discrimination If someone carries a risk variant that could limit their chances of getting a kidney transplant, especially for individuals of African ancestry, there's this real concern about equity and fairness. And that's why the decision around testing has to be guided by both evidence and equity. Another fear people raise is about insurance. If insurers had access to this genetic information, whether for people with kidney disease or those who are completely healthy, will that mean higher premiums or new barriers to coverage? And so, no, it's not just about the science, of the test. It's also about the support provided for patients. Genetic counselors and psychologists are critical in helping individuals navigate these results and manage the anxiety that may come with them.

Dr. Campbell:
So, before we close, are there any final messages either of you would like to leave with your listeners? We'll start with Dr. Ilori.

Dr. Ilori:
As we wrap up, I want to leave us with this charge. Let's spread awareness about APOL1 kidney disease, especially among those at risk. Testing matters, because the research is still evolving and there are many more important questions that we need to answer. But just as important as the science is the equity, we need to make sure that people who choose to be tested are supported, results are handled fairly, and no one is left behind. And finally, community engagement is key. We need participation in clinical trials and studies, and just as important we need to share those results back with the community most impacted. This is how we build trust, advance knowledge, and make a difference together. In summary, let's spread awareness. Let's ensure equity in testing, and let's bring research results back to the communities most at risk.

Dr. Campbell:
Thanks so much. And Josh?

Joshua Albright:
My final message is really about trust and importance of genetic testing. When I first went through this, I had to learn to trust my doctor and the care team that was walking with me. The trust made it possible for me to accept my diagnosis, get into a clinical trial, and believe that there was still hope for my future. Genetic testing played a huge role in my story. It didn't just give me answers. It placed me in the study that I'm in today, and I truly believe that it was a major part of saving my life. Even more importantly, genetic testing also led to my brother being tested and diagnosed. And without that, we may not have caught his kidney disease early. So, for me, genetic testing isn't just about risk, it's about giving families a chance to act, prepare, and support one another. So, I truly believe if we keep pushing for awareness, access, and support around APOL1 testing, I hope more patients have stories that are similar to me and my brother’s and my family.

Dr. Campbell:
Yeah. Such an important perspective. I'd like to thank my guests, Dr. Titi Ilori and Mr. Joshua Albright for joining me. It was great having you both on the podcast

Joshua Albright:
Thank you for having us.

Dr. Ilori:
Thank you so much for having us.

Dr. Campbell:
I'm Dr. Kirk Campbell to access this and other episodes in our series, visit kdigo.org/podcast. Thanks for listening.